

CareDimensions®

Compassionate expertise for advanced illness



Respiratory Care Program

A specialized program for people living with advanced lung disease

Patient and Caregiver Handbook

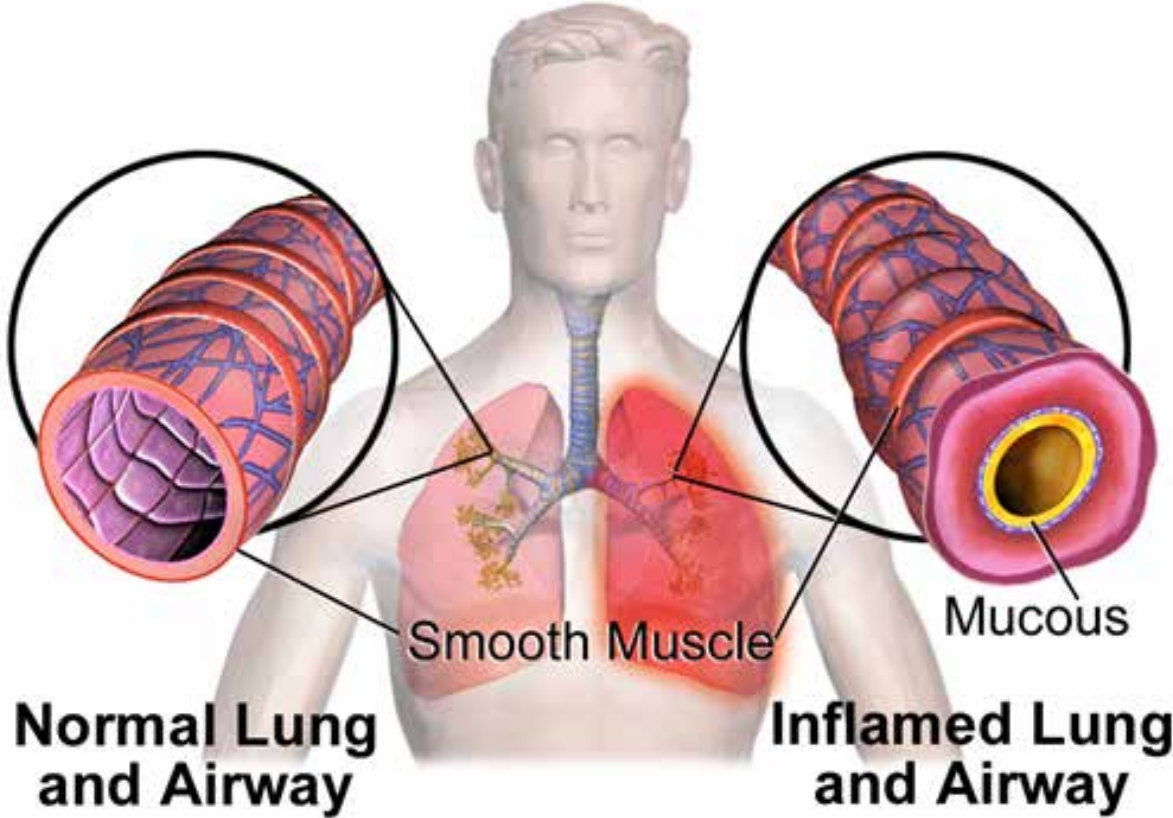
What You Need to Know about Your Lungs

As you breathe, air (oxygen) travels down through your airways and reaches the air sacs or alveoli in the lungs.

The alveoli are tiny balloon-like airs sacs where the exchange of oxygen and carbon dioxide takes place. They are surrounded by blood vessels that take in the oxygen and deliver it through the blood stream to the rest of the body. As your body uses the oxygen, a waste gas is produced called carbon dioxide that the blood carries back to the lungs to be expelled as you exhale.

Gas exchange is the process of getting oxygen into your body and expelling carbon dioxide.

For more information, or to reach the 24/7 Nurse Triage, please call 888-283-1722.



RESOURCES

- American Lung Association www.lung.org
- Centers for Disease Control & Prevention www.cdc.gov/copd
- American Thoracic Society www.thoracic.org
- COPD Foundation www.copdfoundation.org

What are Chronic Lung Diseases?

There are several categories of chronic lung diseases:

Chronic obstructive pulmonary disease (COPD)

- Chronic bronchitis
- Emphysema
- Asthma

Restrictive (interstitial) lung disease

Other conditions

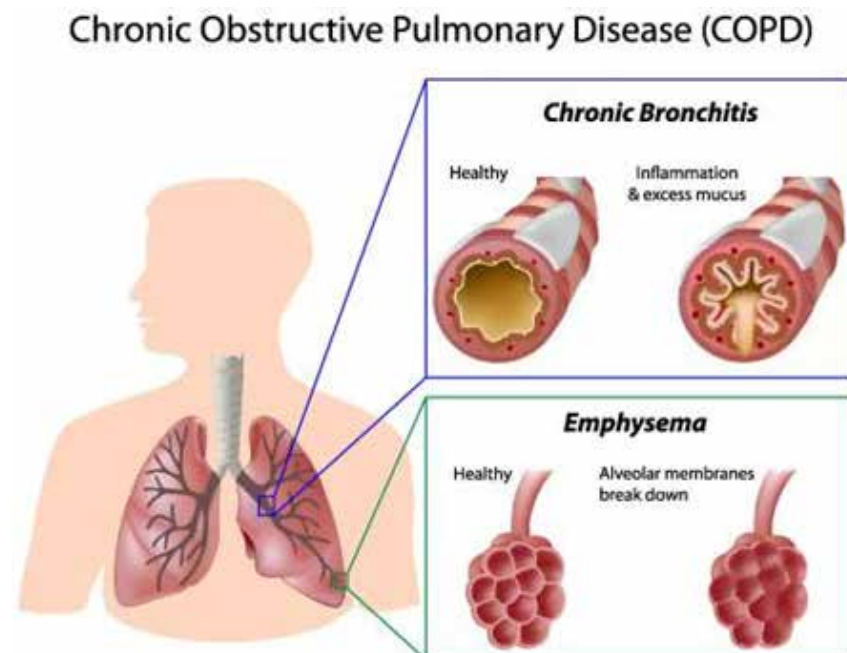
What is COPD?

COPD is an obstruction in the airways that makes breathing harder and may affect the process of gas exchange. This condition is mostly caused by smoking.

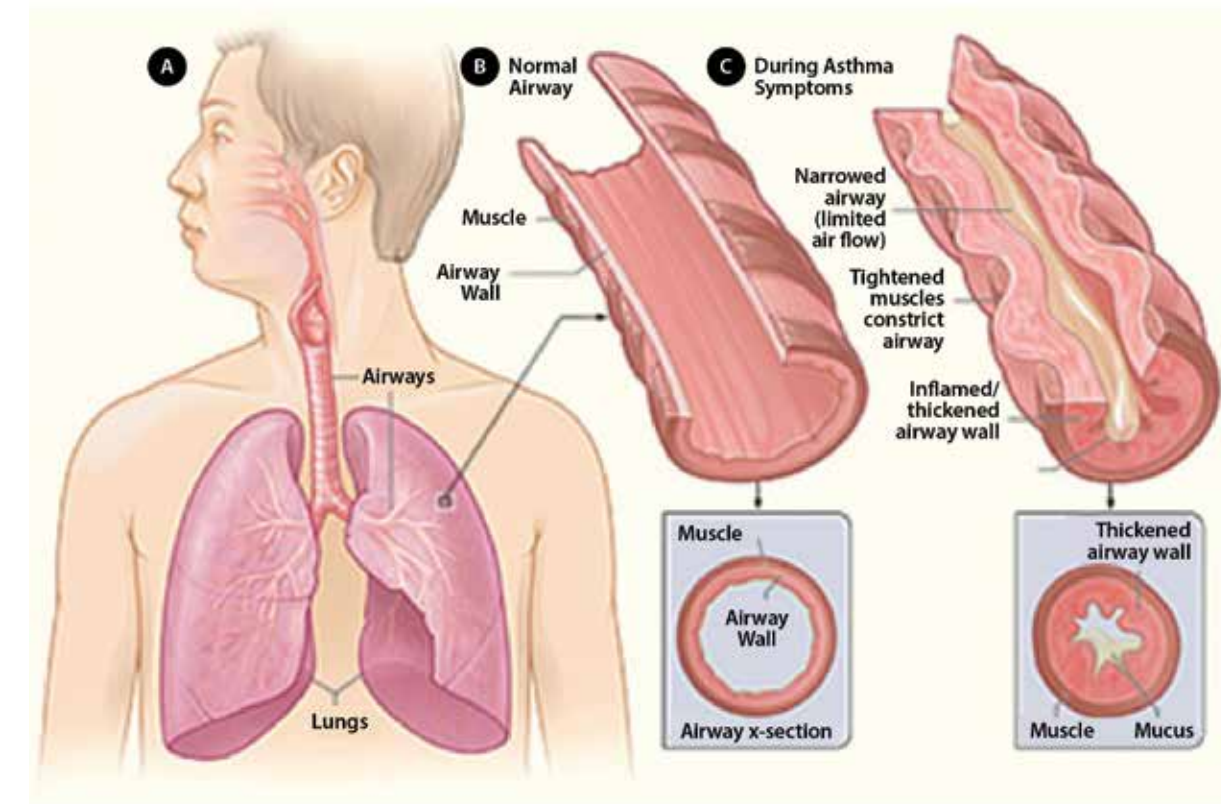
CATEGORIES OF COPD:

Chronic bronchitis is an inflammation (or irritation) of the airways (also called bronchial tubes) in the lungs. When the airways are irritated, thick mucus forms in them. The mucus plugs up the airways and makes it hard for air to get into your lungs.

Emphysema is a condition in which the airways of the lungs are damaged and lose their elasticity or stretchiness. This causes your airway to collapse, trapping the air in the sacs, which makes breathing harder and decreases the amount of oxygen that enters the blood vessels.



Asthma is also a chronic lung disease where the airways in your lungs become inflamed and narrowed. When you have an asthma attack the muscles that surround the airway both tighten and spasm making it difficult to breathe.



What is a Restrictive or Interstitial Lung Disease?

This disease occurs when there is scarring to the lungs causing the airways to be inflexible and stiff. When this occurs, it interferes with the process of oxygen entering the blood vessels, which makes breathing more difficult.

OTHER CHRONIC LUNG DISEASES ARE:

- Cystic Fibrosis
- Lung Cancer

Techniques for Managing Symptoms of Chronic Lung Disease

BREATHING RETRAINING

As a person with a chronic lung disease, you need to learn techniques to assist you with inhaling and exhaling to move oxygen in and out of the lungs.

One of the most basic, but helpful, things you can do to improve the quality of your breathing is **Pursed-Lip Breathing**.



HOW TO:

- Relax your neck and shoulder muscles.
- Inhale slowly through the nose.
- Exhale slowly (about twice as long as your inhale) through pursed or tightly pressed lips.

YOU CAN DO THIS TECHNIQUE ANYTIME OR ANYWHERE!!

Shortness of Breath (Dyspnea) – Tracking Your Symptoms

One of the most common symptoms you may experience when diagnosed with a chronic lung disease is dyspnea or shortness of breath.

The Dyspnea Scale rates your shortness of breath on a scale from 1-10 when you exercise or perform activities of daily living (ADLs)

0	Nothing at all
0.5	Very, very slight (just noticeable)
1	Very slight
2	Slight (light)
3	Moderate
4	Somewhat severe
5	Severe (heavy)
6	↓
7	Very severe
8	↓
9	↓
10	Very, very severe

Be aware of your dyspnea symptoms so that you can report them to members of your medical team.

The Dyspnea Cycle



The dyspnea cycle is a sequence of events that starts with shortness of breath that leads to anxiety and panic, which creates even more shortness of breath and even more anxiety and panic. This cycle affects your quality of life, your independence and emotional health.

Breaking the Dyspnea Cycle

- Do pursed-lip breathing.
- Do some progressive relaxation techniques, described below.
- Conserve your energy. Pace yourself!

RELAXATION AND AIRWAY CLEARANCE TECHNIQUES

One way to stop the dyspnea cycle is by practicing some techniques that will help you relax when you are short of breath. Practice these relaxation techniques daily.

PROGRESSIVE RELAXATION TECHNIQUE:

- Sit in a quiet room or lie down.
- Do pursed-lip breathing.
- Tighten a muscle in your body like your feet or hands and hold the tension while you breathe in.
- Relax the muscle when you breathe out.
- Repeat the steps 3 and 4 with another part of your body such as your arms or legs. You can start from your feet and work your way up.

VISUALIZATION TECHNIQUE:

- Sit in a quiet room or lie down.
- Picture yourself relaxed in a peaceful setting and use your imagination to fill in specific details.
- Keep those images in your mind.
- Refocus if other images attempt to take over your visualization and concentrate on your breathing.

AIRWAY CLEARANCE TECHNIQUE:

- Coughing technique — the “Huff” — combines breathing techniques with coughing. This helps you cough without wearing yourself out.
 - Sit up.
 - Take a breath that is a little deeper than normal.
 - Use your stomach muscles to blow air out in three breaths, making a Ha Ha Ha sound. It is like huffing or blowing onto a mirror or window to steam it up.

Medications

Your health care professional may prescribe medication, inhalers and nebulization treatments to cope with dyspnea, anxiety and other symptoms.

Here are some medications that may be prescribed to treat your chronic lung disease:

TYPES OF MEDICATIONS	HOW THEY WORK
Bronchodilators Short-acting beta-2 agonist (SABA) Albuterol Sulfate (Proventil, Ventolin) Xopenex (Levalbuterol)	<ul style="list-style-type: none"> Relaxes and opens the airways Increases movement of cilia to help clear the mucus Helps reduce/prevent wheezing Helps stop attacks Commonly known as rescue medication
Long-acting beta-2 agonist (LABA) Salmeterol, Serevent, Formoterol*	<ul style="list-style-type: none"> Relaxes and opens the airways Takes effect more slowly and works longer than short-acting beta-2 agonists Increases movement of cilia to help clear mucus Helps prevent exercise-induced wheezing
Anticholinergics Ipratropium + Albuterol (Atrovent, Combivent)	<ul style="list-style-type: none"> Relaxes and opens the airways Takes effect more slowly than short-acting beta-2 agonist
Corticosteroids Oral - Prednisone Inhaled - Flovent, Fluticasone	<ul style="list-style-type: none"> Reduces inflammation and swelling in the airways Reduces mucus production Decreases sensitivity of airways to irritants and allergens
Selective phosphor diesterase-4 enzyme (PDE) inhibitor Roflumilast (Daliresp) Apremilast	<ul style="list-style-type: none"> Reduces number of flare-ups or worsening symptoms (breathlessness, cough, excess mucus) due to bronchitis form of COPD
Inhaled Combination Medications Beta 2 agonist + inhaled corticosteroid Salmeterol + Fluticasone (Advair) Formoterol + Budesonide (Symbicort)	<ul style="list-style-type: none"> Combines effects of different types of medications
Methylxanthines Theophylline	<ul style="list-style-type: none"> Stimulates the diaphragm and breathing May be useful if symptoms occur during sleep Are long acting Levels need to be monitored

* Requires Hospice MD approval

Using Your Inhaler

One of the methods to deliver lung medications is an inhaler. Some of the lung medications that you may be prescribed by your doctor come in a fine mist, a powder or a spray and are often taken by using an inhaler.

Your doctor may recommend that you use a spacer to help deliver more of the medication into your lungs.

HOW TO USE YOUR METERED-DOSE INHALER:

- Shake the inhaler (3-4 times).
- Remove the cap or cover.
- Breathe out.
- Put the inhaler in your mouth between your teeth and close your lips around it tightly. (Alternatively, your doctor may recommend holding the inhaler 1-2 inches from your open mouth. Please follow your doctor's recommendation).
- Spray one (1) puff by pressing down on the inhaler and start to breathe in slowly, between 5-10 seconds if possible. Then breathe out slowly.
- Repeat step 5 after 30 seconds if a second puff is prescribed or needed.

NOTES



HOW TO USE YOUR METERED-DOSE INHALER WITH A SPACER:

1. Remove the cover for both the inhaler and the spacer. Shake the inhaler (3-4 times) and attach it to the spacer.
2. Breathe out.
3. Put the spacer between your teeth and close your lips tightly around it. Position your chin up.
4. Spray one (1) puff by pressing down on the inhaler and breathe in as deep and slowly as possible (5-10 seconds).
5. Repeat step 4 after 30 seconds if a second puff is prescribed or needed.

NOTES

1	2	3	4	5	6	7	8	9	10
11	12	13	14	15	16	17	18	19	20
21	22	23	24	25	26	27	28	29	30
31	32	33	34	35	36	37	38	39	40
41	42	43	44	45	46	47	48	49	50
51	52	53	54	55	56	57	58	59	60
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81	82	83	84	85	86	87	88	89	90
91	92	93	94	95	96	97	98	99	100
101	102	103	104	105	106	107	108	109	110
111	112	113	114	115	116	117	118	119	120
121	122	123	124	125	126	127	128	129	130
131	132	133	134	135	136	137	138	139	140
141	142	143	144	145	146	147	148	149	150
151	152	153	154	155	156	157	158	159	160
161	162	163	164	165	166	167	168	169	170
171	172	173	174	175	176	177	178	179	180
181	182	183	184	185	186	187	188	189	190
191	192	193	194	195	196	197	198	199	200

When to Replace Your Inhaler

1. When you get a new inhaler, check how many puffs it contains.
2. Track how many puffs you use on a daily basis.
3. If you use your inhaler daily, divide the total number of puffs in your inhaler by the number you take daily to determine how many days your inhaler will last.
4. If you use your inhaler once in a while, keep a log of the number of puffs you have used, or you can use the number chart above by crossing off a number each time you use a puff.

Using Your Nebulizer

Your doctor may prescribe medications that are delivered with a nebulizer machine that vaporizes the liquid medication for your lungs into a fine mist. Nebulizers deliver medications very quickly and directly to the lungs and requires very little effort to use because the mist flows continuously. Using a plastic mouthpiece or mask, you will breathe in the medication for 10 to 15 minutes or until the mist stops.

HOW TO USE YOUR NEBULIZER OR COMPRESSOR MACHINE:

1. Wash your hands before and after the procedure.
2. Unscrew the medical cup from the medication bowl of the machine and add the medication as prescribed. Screw the top back on.
3. Place the compressor on a steady surface and at least 12 inches away from any object that could block the flow of air into the compressor (i.e. a wall).
4. Turn the compressor on and put the mouthpiece in your mouth or bring mask to your mouth and nose. If possible, sit in an upright position.
5. Treatment should last about 10-15 minutes, breathing normally, or until the mist stops.
6. Clean the nebulizer mouthpiece or mask and medication bowl after each treatment by removing the T-piece and mouthpiece and disassembling the medication chamber. Rinse the parts under hot water. If used for more than one week, clean with a solution of equal parts vinegar and water.



Oxygen Therapy

You may be prescribed supplemental oxygen if your test results show you have too little oxygen in your blood. Below are images of equipment you may need for your supplemental oxygen.



Top left: Mask.

Top right: Nasal cannula.

Bottom left: Compressed oxygen (oxygen that is stored in a pressurized tank).

Bottom right: Oxygen concentrator (takes oxygen from the air and concentrates it; runs on electricity or battery)

Oxygen Safety Do's and Don'ts

DO:

- Keep oxygen unit at least 3 feet away from any source that may start a fire. Examples: matches, candles, cigarettes (smoking), gas stove (burners), radiators, space heaters, furnaces, fireplaces or any source of open flame.
- Turn off the oxygen unit when not in use.
- Keep the oxygen unit away from direct sunlight.
- Clean the filters on a weekly basis with warm water (or as directed by the oxygen supply company).
- Put up "NO Smoking" or "Oxygen in use" signs in your home for visitors to see.
- Protect the oxygen tubing from kinks and damage from furniture, doorjambs and pets. Do not lay objects on tubing or run it under carpeting.
- Portable oxygen tanks should be transported in the back seat or trunk of the car.

DON'T:

- **Do not smoke** or allow others to smoke in your home, as it could start a fire.
- Do not use petroleum-based products (such as Vaseline, A&D ointment or vapor rubs) while using your oxygen. Mixing these with oxygen may cause burns. Instead use water-based products (such as K-Y jelly).
- Do not use aerosol sprays such as air fresheners and hair spray. These sprays are very flammable.
- Do not use oxygen while cooking on a gas stove.
- Do not plug your oxygen concentrator into an overcrowded outlet or extension cord.
- Do not leave the tubing in your bed or under furniture cushions. If you accidentally leave the unit on while you are not using it, the oxygen will leak into these items. A spark or flame could cause a fire.



Humidifier Bottles

USING YOUR HUMIDIFIER BOTTLE:

- You should only use a humidifier bottle for liter flow of 4 liters/minute or more. Do not change your liter flow without consulting your doctor.
- If nasal dryness occurs, use a nasal saline spray or a water-based lubricant, such as K-Y jelly. Do not use oil-based ointments like Vaseline to lubricate, as they are flammable.



Left to right: Bottle with nasal cannula connection; O2 Concentrator; Connector

CARE AND CLEANING OF THE HUMIDIFIER BOTTLE:

- **ONLY** use distilled water in the humidifier bottle. Do not fill it past the maximum fill line. Check water level often.
- Daily, remove the humidifier cup from the concentrator and discard any remaining water.
- Use back-up oxygen while cleaning and filling the humidifier bottle.
- Weekly, disinfect the humidifier bottle by soaking in warm soapy water for a minimum of 20 minutes, then rinse using an equal parts vinegar/water solution and let it air dry.

HOW TO INSTALL YOUR HUMIDIFIER BOTTLE:

- Using distilled water fill the humidifier bottle half way. Do not fill over the maximum line.
- Attach the humidifier adapter to the top of the humidifier lid. Do not cross-thread the lid, as this will cause a loss of oxygen.
- Place the bottle into the concentrator tray.
- Connect the humidifier adapter onto concentrator nozzle.
- Connect cannula and or tubing onto humidifier bottle nozzle.

Caring for a Loved One with Chronic Lung Disease

At Care Dimensions, we care for not only the patient, but also his/her family and caregivers by providing support and education.

While your primary focus as a caregiver is providing the best care to your loved one, it's also critical that you take care of yourself. It's easy to get overwhelmed and normal to have many questions about providing care. Your hospice team can answer any questions that you may have. Here are a few examples:

1. Where can I find support and help with my love one?
2. How can I keep track of all the medications and treatments?
3. What signs and symptoms should I report?

Your interdisciplinary hospice care team includes a hospice physician, hospice nurse case manager, social worker, chaplain and a hospice aide, if needed. The hospice team works with your loved one's primary physician who will prescribe any medications and treatments. We all work together to help manage your loved one's chronic lung disease symptoms and prevent hospitalizations.

You and your loved one are critical members of the care team, because you are the best advocates for and monitors of your loved one's overall health and symptom management. It's important to share with us any changes in symptoms, problems with mobility or activities of daily life, issues with equipment or the starting and stopping of any medications.

Our combined goal is to prevent any symptom flare ups and any further hospitalization.

Your Role as a Patient or Caregiver

Please report any new and ongoing symptoms to your medical team.

Use the Advance Respiratory Disease Action Plan on the next page to help you determine what you can do at home to treat symptoms and when symptoms need the attention of your medical team.

Green Zone Symptoms indicate the patient is doing well.

- Usual activity and exercise level
- Usual amounts of cough and phlegm/mucus
- Sleep well at night
- Appetite is good

Actions to follow:

- Take daily medicines
- Use oxygen as prescribed (if patient uses oxygen)
- Continue regular exercise/diet plan
- At all times avoid cigarette smoke and inhaled irritants

Yellow Zone Symptoms indicate the patient is having a bad day or a flare up.

- More breathless than usual
- Less energy for my daily activities
- Increased or thicker phlegm/mucus
- Change in color of phlegm/mucus
- Using quick relief inhaler/nebulizer more often
- Swelling of ankles/lower extremity more than usual
- More coughing than usual
- Symptoms like having a "chest cold"
- Poor sleep and any symptoms cause you to wake up
- Appetite is not good
- Medication is not helping

Actions to follow:

- Continue daily medications
- Use quick relief inhaler as prescribed
- Start Prednisone if prescribed
- Start an antibiotic if prescribed
- Use oxygen as prescribed
- Get plenty of rest
- Use pursed lip breathing
- Call Care Dimensions Triage Nurse for an evaluation.

**24/7 Nurse Triage
888-283-1722**

Red Zone Symptoms indicate urgent care medical needs requiring immediate evaluation by Care Dimensions.

- Severe shortness of breath even at rest
- Not able to do any activity because of difficulty breathing
- Not able to sleep because of difficulty breathing
- Fever or shaking chills
- Feeling confused or very drowsy
- Chest pains
- Coughing up blood

Actions to follow:

Call Care Dimensions Triage Nurse immediately for an evaluation:

**24/7 Nurse Triage
888-283-1722**



Compassionate Expertise for Advanced Illness

Care Dimensions, one of the nation's first hospice programs and the region's largest, provides services in more than 90 communities in Eastern Massachusetts.

As a non-profit, community-based leader in advanced illness care, we honor diversity and welcome patients of all race, color, national origin, age, disability, religion, sexual orientation or gender expressions. Our services include:

- Hospice
- Palliative care
- Specialized care programs: *Dementia, Cardiac and Lung Diseases, Pediatrics, Developmentally disabled adults*
- Meeting the unique needs of: *Veterans and the LGBTQ community*
- Kaplan Family Hospice House and Care Dimensions Hospice House
- Grief support
- Education and training

Main: 888-283-1722

Referrals: 888-287-1255

Referral Fax: 978-774-4389

CareDimensions.org



WE HONOR VETERANS



ATTENTION: If you do not speak English, language assistance services, free of charge, are available to you. Call 1-888-283-1722 (TTY: 7-1-1).

ATENCIÓN: si habla español, tiene a su disposición servicios gratuitos de asistencia lingüística. Llame al 1-888-283-1722 (TTY: 7-1-1).

ATENÇÃO: Se fala português, encontram-se disponíveis serviços linguísticos, grátis. Ligue para 1-888-283-1722 (TTY: 7-1-1).